"More Damaging than a Scalpel": Scientific Literacy and the Moderation of Psychological Distress from Susceptibility Genetic Testing

Lilliana Haight

Abstract: *In the current age of scientific advancement, clinical and direct-to-consumer susceptibility genetic tests are significantly improving the opportunities for individuals to explore and address their risk of developing various hereditary diseases. Despite the enhanced abilities that genetic analysis affords, however, the potential for this technology to have adverse psychological consequences for consumers has provoked ongoing medical, scientific, and societal controversies regarding the safety of its use. This essay argues that susceptibility genetic testing is not inherently harmful but that engaging in scientific literacy is vital to enjoying a healthy testing experience. The essay exposes the powerful role of information in alleviating the psychological distress that could be encountered through genetic testing: If consumers are knowledgeable of the benefits, risks, and constraints of a susceptibility genetic test, they might avoid symptoms of psychological harm because they will be better equipped to make appropriate, informed decisions regarding their use of the technology.*

Keywords: scientific literacy, susceptibility genetic testing, psychological distress, emotional health, direct-to-consumer

As the capabilities of genetic analyses have improved, genetic testing for disease susceptibility (also known as susceptibility genetic testing or predictive genetic testing) has become a common method for determining a patient's risk for developing certain hereditary diseases, such as breast cancer and Alzheimer's disease. By identifying disease-linked mutations in

otherwise healthy patients, these tests have given genetically vulnerable individuals the opportunity to pursue preventative treatments for disorders before they become disabling. Consequently, the use of susceptibility genetic testing has become prevalent in both direct-to-consumer (DTC) and clinical settings over the past twenty years. According to an article on *MedlinePlus*, over 77,000 different genetic tests have been made available since July 2021 ("What Is Genetic Testing?").

The escalated consumption of these tests, however, has stimulated extensive debate among experts regarding the psychological implications of genetic testing. Some fear that unfavorable test results elicit emotional distress in consumers by giving them reason to worry that they will develop a disease in the future. In addition, inaccurate or unclear results could generate unnecessary stress in participants and lead them to make unhealthy, irrational decisions. Others claim that susceptibility genetic tests do not cause any significant emotional harm but instead serve to mitigate emotional distress by providing concerned participants with a sense of knowledge and control of their health (Broadstock et al. 735; Heshka et al. 27). While each of these opposing views seems to be founded on direct observation, closer inspection reveals that scientific literacy has played a key role in constructing the evidence for both perspectives.

I argue that genetic testing for disease susceptibility can indeed generate psychological distress in consumers but that this effect is primarily observed when participants are not familiar with the nature of the genetic testing process, particularly its risks and limitations. Through analysis of consumers' emotional reactions to the results of different kinds of susceptibility

genetic tests, my research has illuminated a distinct correlation between scientific literacy and psychological health—namely, the less informed test participants are regarding the testing process, the more likely they are to misinterpret their test results and experience psychological distress. On the contrary, individuals who have a sound understanding of the genetic testing process and its implications will be better able to interpret and respond to their test results while preserving their emotional health.

In an NPR podcast discussing the current issues with genetic testing, Dr. Hank Greely, a professor of law and biosciences at Stanford University, comments on the powerful influence that scientific literacy has on the genetic testing process: "Information can be more powerful and more damaging than a scalpel" ("Genetic Testing"). Indeed, scientists acknowledge that information regarding genetic analysis can have significant implications for test consumers, and they have consistently emphasized this understanding in published literature. However, researchers have thus far provided only vague explanations of *why* scientific literacy is essential to the genetic testing process. If scholars cannot clearly delineate the reasons why it is necessary to approach genetic testing with a thorough understanding of it, individuals will fail to appreciate the dangers of scientific illiteracy and continue engaging in genetic testing as uninformed consumers. Therefore, by revealing the effect that scientific knowledge has on psychological health, I offer a distinct reason why consumers should be knowledgeable of the current limitations of genetic analysis before they participate in susceptibility genetic testing.

Perceived Insignificance of Susceptibility Genetic Testing to Psychological Distress

In the past, scholars have conducted research to examine the psychological effects of susceptibility genetic tests on consumers. Some of these investigations have concluded that susceptibility genetic testing does not generate significant emotional distress in consumers. The following two articles are examples of such investigations.

In "Psychological Consequences of Predictive Genetic Testing: A Systematic Review," Marita Broadstock et al. outline the results of a meta-analysis conducted to assess the psychological influence of genetic testing. In the study, the authors identified and analyzed fifteen papers that discussed the effects of genetic tests screening for Huntington's disease, hereditary breast and ovarian cancer, familial adenomatous polyposis, and spinocerebellar ataxia. After examining the papers, Broadstock et al. conclude, "The studies reviewed found no evidence of abnormally high levels of, nor increases in, emotional distress in mutation carriers or noncarriers at any point during three years after predictive genetic testing. Both carriers and noncarriers showed decreased distress after testing, with this being greater and more rapid amongst non-carriers" (735). These researchers found that genetic test results do not cause psychological distress in participants for at least the first three years following testing (731). On the contrary, the researchers concluded that genetic testing actually relieves the distress of participants, particularly those whose results indicate they do not carry a disease-linked mutation.

The findings of Broadstock et al. closely correspond to those of Jodi Heshka et al., who published "A Systematic Review of

Perceived Risks, Psychological and Behavioral Impacts of Genetic Testing." This article summarizes the results of a literature review that investigated how the use of susceptibility genetic testing affects a consumer's psychology and behavior. The review included thirty independent studies that examined the effects of genetic tests screening for hereditary nonpolyposis colorectal carcinoma, hereditary breast and ovarian cancer, and Alzheimer's disease. Discussing the data obtained from these studies, Heshka et al. report, "We found that overall genetic testing had no impact of psychological outcomes such as general and specific distress, anxiety, or depression in either carriers or noncarriers" (27). With this statement, the authors suggest that susceptibility genetic tests do not generate certain psychological consequences in participants following testing.

According to the results of these investigations, scientific research has found evidence suggesting that susceptibility genetic tests do not have significant psychological implications for test consumers. According to the work of Broadstock et al. and Heshka et al., researchers have published at least forty-five studies that sufficiently support this finding. The large amount of accepted research supporting the conclusion that genetic tests do not cause psychological harm signifies that this idea might very well be valid.

Observed Psychological Distress in Susceptibility Genetic Testing

Although Broadstock et al. and Heshka et al. concluded that genetic tests for disease susceptibility do not lead to adverse psychological effects, firsthand accounts seem to directly contradict their findings by drawing attention to the psycho-

logical harm such tests can cause. The following articles relate interviews with several women who had directly participated in susceptibility genetic tests yielding unwelcome results. In these articles, the interviewers testify that genetic testing was observed to have emotional implications for these women, and the patients' personal reflections on their experiences with genetic testing reveal that they did indeed suffer psychological distress.

Inconclusive genetic test results, known as variants of uncertain significance (VUS), can have unnecessary psychological and emotional implications for test participants. On February 7, 2021, the *Washington Post* released an article titled "Ambiguous Genetic Test Results Can Be Unsettling. Worse, They Can Lead to Needless Surgeries." This article, written by Christina Bennett, demonstrates how susceptibility genetic tests can harm society by prompting uninformed patients to prematurely undergo preventative surgeries. In the article, Bennett recounts the stories of Mai Tran and Logan Marcus, two women whose genetic tests revealed that they carry VUS for cancer. The article includes statements from the women that clearly demonstrate their distrust of susceptibility genetic testing and its effects.

Bennett first presents several statements from Mai Tran that illustrate her reluctance to take a genetic test. For example, Tran, who has a family history of breast cancer, states, "I didn't really want to do it" (Bennett). Tran's testimony suggests that she was not comfortable with the idea of undergoing genetic testing, not only before she took the test but also after she had received the results. Because of her family history, Tran already had a high likelihood of developing cancer at some point in her lifetime; the affirmative results of a genetic test could have al-

lowed her to take more effective measures to avoid developing cancer at all. Regardless of the perceived benefit, however, Tran still wishes that she had not taken the test. It is possible that Tran was suspicious of genetic tests because she was unfamiliar with them. Indeed, Bennett later comments that Tran had never heard of VUS before undergoing testing. Because Tran was reluctant to take the test originally, she likely did not make the effort to understand how to interpret her test results when she received them. Nevertheless, with her statement, Tran implies that she does not value knowing her perceived risk as much as she values emotional security.

The testing process itself was observed to be psychologically disturbing for Tran. Bennett mentions that it caused her "emotional turmoil." Bennett's account indicates that, even if genetic tests are ultimately beneficial because of the information they provide, the testing process is not devoid of negative effects. In addition, Tran appears to blame her emotional distress on her gynecologist; she reflects, "I really did the test mostly for my doctor and not for myself. [...] If I could have chosen, I would not have done it" (Bennett). Tran seems to blame her emotional distress on her physician because, as Bennett mentions, the gynecologist had pressured Tran to participate in testing. The fact that Tran ultimately conceded to her physician's wishes illustrates the influence that medical providers have on the genetic testing process—a topic that I will later address. Overall, Tran's testimony reveals the perspective that, even though susceptibility genetic tests can provide useful information, their benefits are not necessarily worth their emotional complications.

Bennett's next interview with Logan Marcus offers evidence that susceptibility genetic testing may result in sustained psy-

chological disturbances, specifically symptoms of depression and anxiety. Marcus, who had received test results indicating that she carried VUS for breast and ovarian cancers, testifies, "This has been a two-plus-year struggle for me. [...] I felt very alone, and nobody could give me any answers" (Bennett). Marcus speaks of experiencing adverse consequences for over two years, a timespan that seems to contradict the three-year period defined by Broadstock et al. Furthermore, Marcus's use of the word "alone" to describe her feelings implies that she felt isolated from those who could help her, such as her family members and healthcare providers. She also felt as though she could not find reliable information from anyone. According to Marcin Owczarek and colleagues, studies have shown that feeling isolated and unsure of who to trust can lead to symptoms of depression and anxiety (586). Susceptibility genetic testing may cause psychological distress by contributing to these conditions.

Another source similarly indicates that genetic tests can cause psychological distress for participants, and it also demonstrates that this effect occurs specifically when participants do not understand how to interpret and respond to their test results. The article "When They Warn of Rare Disorders, These Prenatal Tests Are Usually Wrong" from the *New York Times* relates accounts of individuals who had participated in genetic testing and received inaccurate results. This article, coauthored by Sarah Kliff and Aatish Bhatia and published on January 1, 2022, illustrates that certain prenatal genetic tests screening for rare genetic disorders tend to have high rates of false positives, even if they have been advertised as accurate and reliable. Kliff and Bhatia recorded a summary of their interviews with several

women who had received false positive results from prenatal genetic tests:

> [Fourteen] patients who got false positives said the experience was agonizing. They recalled frantically researching conditions they'd never heard of, followed by sleepless nights and days hiding their bulging bellies from friends. Eight said they never received any information about the possibility of a false positive, and five recalled that their doctor treated the test results as definitive.

This description of the women's responses demonstrates the effect that disturbing results can have on genetic test participants. Words such as "agonizing," "sleepless nights," and "frantically searching" indicate high levels of anxiety in these individuals. Regardless of whether the prenatal tests turned out to be accurate, it is clear that their results caused significant emotional distress in these expectant mothers. Furthermore, the majority of the patients noted that they had not been informed of the tests' known inaccuracy before participating in them. Consequently, they accepted their test results without question and suffered severe emotional distress as a result. The fact that some physicians also misjudged the results suggests that even physicians are not always well-informed of the limitations of genetic tests. Since they were unaware of the tests' false positive rates, the physicians were unable to appropriately help their patients navigate their results and instead caused them even greater psychological distress. The responses of these patients to their prenatal test results illustrate the negative psychological consequences that susceptibility genetic tests can have, especially when individuals are not fully informed of their limitations.

Lastly, Kliff and Bhatia offer an example of the consequences of insufficient information. At age twenty-five, Cloey Canida received a prenatal test result indicating that her baby had a 99% chance of being born with Patau syndrome. Infants afflicted with this condition usually do not survive longer than a week after birth (Kliff and Bhatia). The authors report, "Ms. Canida couldn't stop thinking about the result sheet. She recalls crying during an ultrasound, thinking it was one of the few times she'd see her child moving." It appears that Canida experienced significant psychological distress and anxiety, believing that her baby would die soon after birth. When the test result proved wrong, and she gave birth to a healthy daughter, Canida stated, "I wish that we would have been informed of the false positive rate before I agreed to the test. [...] I was given zero information about that" (Kliff and Bhatia). Canida's testimony reveals that she had not been well informed of her test's limitations before she participated in it. As a result, she experienced undue psychological distress. Looking back, Canida believes that she would have been spared unnecessary emotional suffering if she had been informed of the test's error rate before she pursued it. Her reflection is evidence of the effects that insufficient information can have on the psychological component of the genetic testing process.

Christina Bennett's article illustrates that the genetic testing process can have emotional implications for consumers, a finding that contradicts the research conducted by Broadstock et al. and Heshka et al. to investigate the psychological effects of susceptibility genetic testing. However, the article written by Sarah Kliff and Aatish Bhatia suggests a possible explanation for this difference. The women Kliff and Bhatia interviewed mentioned

that the genetic testing process would have been easier to endure had the tests' known inaccuracies been revealed to them prior to their participation. If they had understood this information, they could have avoided experiencing such significant emotional distress. This idea suggests that scientific literacy plays an important role in directing the psychological outcome of genetic testing.

Scientific Literacy and Susceptibility Genetic Testing

For many years, academics have considered information to play a pivotal role in directing the outcomes of genetic testing. Indeed, many scholars have acknowledged that it is imperative for consumers to be aware of the advantages, disadvantages, and uncertainties associated with genetic tests before they participate in them. They consistently emphasize that genetic testing is unsafe if consumers are not provided with, or if they do not understand, this information.

The term "scientific literacy" is often used in an educational context. The book *Science Literacy: Concepts, Contexts, and Consequences* defines scientific literacy in the following way: "understandings of scientific processes and practices, familiarity with how science and scientists work, a capacity to weigh and evaluate the products of science, and an ability to engage in civic decisions about the value of science" (1). Thus, according to this source, scientific literacy refers to understanding the purposes, methods, and influences of science. In an article published by the *Journal of Educational and Social Research*, Babalola Ogunkola writes, "Scientific literacy defines what the public should know about science in order to live more effectively with respect to the natural world. [...] All that is needed is the facts and vocab-

ulary sufficient to comprehend the context of the daily news" (270). Ogunkola defines scientific literacy in a practical sense, believing that the term generally refers to knowing enough about science to understand real-life events. However, for the purposes of this essay, the term "scientific literacy" has broader applications than the definitions provided by *Science Literacy* or Ogunkola. In the context of genetic testing, I define scientific literacy as the possession of accurate, research-founded knowledge regarding the benefits, risks, implications, and limitations (including fallacies and error rates) related to a genetic test or testing process. Resources that can promote scientific literacy in genetic testing would include educational media sources, genetic and clinical counseling, and direct communication with genetic testing company representatives. In this context, scientific literacy would also involve taking measures to determine the best response to a potential test result; such measures include researching treatment options, consulting appropriate medical specialists, and seeking mental health counseling if needed.

According to Susanne Haga et al., an investigation was conducted to understand how scientific literacy influences consumers' attitudes toward genetic testing. The researchers found that "participants with higher genetic knowledge [...] were more likely to express uncertainty about the impact of genetic testing on a person's future than those with a lower level of genetic knowledge [...] and also more likely to agree with the statement that DNA testing is frightening" (331). The results of this study indicate that the better consumers understand genetics, the more likely they are to engage in genetic testing with caution. Because they understand the limitations of genetic

tests, they can participate in them apprehensively, recognizing that their results are not always as definitive and significant as they seem. It follows, then, that those who are unaware of the medical applications of genetics will not be as guarded in their approach to genetic testing. As a result, they may participate in genetic testing naively—without first understanding its benefits, limitations, and emotional implications in full—and suffer psychological distress as a result. The results of this study serve to manifest the influence that scientific literacy can have on an individual's approach to genetic testing.

Doris Teichler Zallen, a professor in the Department of Science and Technology in Society at Virginia Tech, offers practical guidelines for becoming scientifically literate in the context of genetic testing. She advises that those interested in undergoing susceptibility genetic testing should begin the process by considering four key elements—their risk for disease, the usefulness of the information that would be gained from testing, their individual circumstances at the time of testing, and whether a test's benefits would offset any harmful consequences (10). Zallen advises her readers, "You must [...] examine the environment within which susceptibility-gene testing would be carried out in order to be sure that the necessary components of susceptibility testing—risk assessment, education, choice, interpretation, and support—are suited to your needs" (60–61). Zallen's suggestion that readers ensure they have direct access to educational and counseling services before participating in genetic testing reveals that she deems these resources valuable—if not crucial—to the genetic testing process. Her statement implies that informed individuals would benefit more from participating in genetic testing than less informed individuals.

Lastly, in a statement released by the American Society of Human Genetics (ASHG) regarding DTC genetic testing in the United States, Kathy Hudson et al. agree that insufficient information can have a significant influence on the health of test users. They argue that "consumers are at risk of harm from DTC testing if [...] inadequate information and counseling are provided to permit the consumer to make an informed decision about whether testing is appropriate and about what actions to take on the basis of test results" (637). This assertion indicates that test consumers can suffer harm if they undergo genetic testing without access to enough literacy-promoting resources. Even though it does not delineate the psychological dangers specifically related to genetic testing, the ASHG acknowledges that scientific literacy plays an important role in directing the health of test consumers.

These sources highlight the important role of scientific literacy in the genetic testing process. Although the authors of these sources do not discuss the specific psychological consequences of having insufficient information, they do understand that genetic testing can be harmful for uninformed participants. Therefore, they advise consumers to fully understand the benefits, risks, implications, and limitations of susceptibility genetic tests before participating in them.

Scientific Literacy and Psychological Distress

Genetic tests for disease susceptibility have psychological ramifications, but these effects are only especially significant in participants who do not fully understand the benefits, risks, implications, and limitations of genetic tests before they pursue them. This concept is illustrated in the story of Sasa Woodruff,

a woman who had her stomach surgically removed after a susceptibility genetic test revealed she carried a mutation linked to stomach cancer ("Genetic Testing"). Although Woodruff's test results seemed to cause her moderate emotional distress at one point in the testing process, her endeavors to become scientifically literate ultimately allowed her to experience a positive outcome from genetic testing.

Woodruff's story is narrated in the NPR podcast episode "Genetic Testing: Is It Better Not to Know?" This podcast, released on May 13, 2022, discusses the complex issues of whether individuals should use unconfirmed genetic test results to make major decisions for their health if there is no other information available to them and whether they should be allowed to access their own genomic information if they are not trained to properly interpret it. In the podcast, Mary Louise Kelly provides a recording of her co-host Ari Shapiro's interview with Nita Farahany and Hank Greely, two experts on the implications of advancing biotechnologies. The three speakers base their discussion on Shapiro's recent interview with Woodruff.

Woodruff's story illustrates that genetic testing *can* have a positive influence on individuals, in some cases. With a family history of breast and colorectal cancer, Woodruff had previously taken genetic tests to search for these cancer markers, but the results had indicated that she was not at risk. In response, Woodruff recalls, "It was this really joyous moment because I thought [...] I don't have to worry about this cancer [...] anymore. And then that was that" ("Genetic Testing"). Woodruff felt extremely relieved when her test results indicated that she was not a carrier for the diseases known to be prevalent in her family. Her reaction is consistent with the idea that genetic test results can

decrease distress levels if they indicate that the patient is a noncarrier for the candidate disease. The finding parallels that of Broadstock et al., who found that participants determined to be noncarriers of a disease displayed a greater and more rapid post-test decline in distress levels than participants determined to be carriers (735). In this case, it appears that Woodruff experienced a positive outcome from participating in genetic testing.

However, Woodruff's relief was short-lived. Years later, the medical director of Telligen Cancer Genetics, Dr. Richard Frieder, told her that new research indicated she carried the CDH1 mutation, which is associated with stomach cancer. When she received this news, Woodruff remembers, "I was shaking and just really flustered" ("Genetic Testing"). Like the two women interviewed by Christina Bennett, Woodruff also suffered distress when she learned that she was susceptible to developing a serious cancer. However, after consulting a genetic counselor and researching her mutation, she decided to undergo surgery to have her stomach removed. Six months later, Woodruff tells Shapiro, "I'm really thankful for [being informed of the mutation] now" ("Genetic Testing"). This abrupt shift in Woodruff's attitude toward her test results can be attributed to the fact that she properly responded to them by undergoing preventative surgery. Knowing that she has removed the organ where cancer could develop has given Woodruff peace and made her grateful to have participated in the genetic test.

Woodruff's ultimate reaction to her test results was quite different from the reactions of Mai Tran, Logan Marcus, Cloey Canida, and the other patients previously mentioned, but closer inspection reveals that scientific literacy had been the underlying reason for this distinction. According to Kelly, Woodruff

"spent years investigating the CDH1 mutation before making the difficult decision to get her stomach removed" ("Genetic Testing"). Woodruff devoted a large amount of time to researching her mutation and considering various treatment plans before finally arriving at her decision. Her effort to fully understand her test results before taking any action allowed her to protect her emotional health. In contrast, the other women were essentially uninformed of the details of genetic testing. For example, the observations that Tran had never wanted to undergo testing in the first place and that she had not understood the meaning of VUS until she had already taken the test (Bennett) are evidence of her unfamiliarity with genetic testing. Because Marcus noted that she had not been able to find answers (Bennett), it is clear that she had not been able to understand the meaning of her test results either. Cloey Canida personally testified that she had not been informed of her test's false positive rate prior to using the test (Kliff and Bhatia). According to Kliff and Bhatia, 8 of the 14 patients they interviewed also testified that they were unaware of their prenatal tests' known inaccuracy when they participated in them. Hence, the effect that a lack of knowledge had on the emotional health of these women was significant in that they suffered severe emotional distress by participating in genetic testing as uninformed consumers. If these women had been fully informed of the nature of genetic testing just as Woodruff had, they likely would have been relieved of psychological distress.

The influence that scientific literacy has on the genetic testing process now explains why the research of Broadstock et al. and Heshka et al. suggests that susceptibility genetic tests do not cause psychological harm, even though other accounts in-

dicate that they do. The studies that Broadstock et al. reviewed fail to mention the quality and amount of educational or counseling services participants were offered during the testing process, and the researchers do not consider how the availability of such resources may have influenced their findings. In the study presented by Heshka et al., the researchers fail to point out the effect that information and educational resources may have had on the results of this study. While they acknowledge that "most studies included standard genetic counseling procedures that included information about the disease, its mode of inheritance, the gene defect, the benefits, risks and limitations of genetic testing, overview of screening recommendations, and treatment and preventive options" (Heshka et al. 30), the researchers do not recognize that this information may have confounded the results of the studies. Since the participants were provided with educational resources, they would undoubtedly have been able to more easily cope with any unexpected test results they encountered than if they had not been offered these resources. In reality, the research of Broadstock et al. and Heshka et al. actually serves to support my argument by demonstrating that the availability of educational resources can mitigate the emotional distress that consumers encounter in the genetic testing process.

Sasa Woodruff's overall experience with susceptibility genetic testing underscores the importance of scientific literacy. Woodruff's access to information about her test results, combined with her endeavors to fully understand and properly respond to this information, was the prevailing reason why she did not experience prolonged psychological distress like the other patients previously mentioned. Thus, this NPR podcast

illustrates that individuals can suffer significant psychological distress from susceptibility genetic testing in the absence of adequate and reliable information but that this distress can be avoided if test consumers are equipped to correctly interpret and respond to their results.

Promoting Scientific Literacy in Society

Currently, there exists a conspicuous void in the amount of information made available to consumers navigating the testing process. Consumers cannot be expected to fully understand the implications of genetic testing if information is not provided to them. Therefore, scholars have proposed several measures that may be taken to provide test users with a more thorough understanding of the implications of genetic testing.

Some scholars are concerned that genetic testing companies do not offer consumers comprehensive information regarding the accuracy and validity of their tests so as not to deter prospective buyers from purchasing their products. Cheryl Berg and Kelly Fryer-Edwards suggest that the scientific illiteracy of test participants is due to the unethical practices of genetic testing companies and therefore counsel, "[Companies] must provide enough information for consumers to make educated decisions, market only clinically valid tests and reduce the potential for misinterpreting genetic test results" (29). Because genetic testing companies exercise significant control over the amount and quality of information that is available to consumers, it is crucial that they provide complete and accurate information about their products. This is especially important in the DTC domain, where medical professionals may not be as involved in the genetic testing process.

Alternatively, other scholars believe that the scientific illiteracy of consumers in the United States can be attributed to lenient federal regulations. In discussing the role of the United States Food and Drug Administration (FDA) in the advertisement and sale of DTC genetic tests, Catherine Sharkey et al. write, "Without the specter of FDA oversight, DTC [genetic testing] companies are not forced to provide, and therefore might not produce, underlying scientific data and information" (287). The authors believe that increased federal oversight would motivate genetic testing companies to provide consumers with more detailed information regarding their products.

Finally, scholars reason that if healthcare professionals, such as physicians and genetic counselors, have a sound understanding of genetic testing, patients participating in genetic testing will consequently be better informed. Suzanne Feetham and Elizabeth Thomson write, "It is critical that health professionals be aware of both the promises and pitfalls of undergoing genetic testing. This will allow them to assist individuals and their families in deciding whether they wish to undertake genetic testing. Health professionals need to understand that sometimes these tests will not tell them what they want to know" (22). As influential figures in the genetic testing process, medical providers have the power to effectively guide patients toward making appropriate decisions regarding genetic testing. However, they are equally able to misguide patients if they themselves are not familiar with the pitfalls of genetic testing. Indeed, the patient testimonies provided by Bennett and Kliff and Bhatia illustrate that physicians can significantly influence whether patients participate in genetic testing and how they manage their results. For example, Mai Tran's gynecologist had

pressured her to participate in genetic testing even though she did not feel emotionally prepared, and ultimately Tran had conceded. Five of the fourteen patients interviewed by Kliff and Bhatia testified that their physicians had upheld the results of their tests in spite of the tests' known inaccuracies. Because healthcare professionals can exert such a strong influence over their patients, they can cause psychological harm if they themselves do not have a sound understanding of genetic testing. For this reason, Feetham and Thomson recommend that, before guiding patients through the genetic testing process, medical providers familiarize themselves with the applications of genetic tests while also understanding their present shortcomings.

These scholars have proposed specific changes that could be made to improve the availability and reliability of information for genetic test consumers. Yet even if these changes are implemented on a large-scale basis, test users should still independently strive to research and explore the implications of genetic tests before participating in them. Regardless of the amount and quality of available information, it is ultimately the duty of individual consumers to carefully seek appropriate resources, examine information accurately, and scrutinize any data they find. Endeavors to promote scientific literacy in susceptibility genetic testing will help consumers make the most responsible, informed decisions possible.

Conclusion

Genetic tests can significantly influence the psychological and emotional health of consumers if they yield troubling, inconclusive, or inaccurate results. However, symptoms of psychological distress are primarily significant only for individuals

who are not familiar with the current nature of genetic testing before they participate in it. It is therefore of utmost importance that the consumers of clinical and DTC genetic tests for disease susceptibility be scientifically literate in this field, so that they can appropriately respond to their test results and avoid psychological distress.

In this essay, I have discussed the psychological implications associated with genetic testing for disease susceptibility and demonstrated the pivotal contribution that scientific literacy makes to this issue. Further research is necessary to determine whether the relationship between scientific literacy and psychological health extends beyond susceptibility genetic testing to also encompass DTC genetic tests used for other purposes—exploring ancestry, identifying nationality, and learning more about personal traits—as well as other clinical tests known to yield open-ended results. It could be that thoroughly educating test participants on scientists' current understanding of such analyses would help alleviate any associated emotional discomfort.

Within the current genetic testing era, the widespread implementation of genetic testing in both the clinical and the consumer domains is inevitable; the use of genetic testing can only be expected to increase in the future. This means that many individuals will take a susceptibility genetic test at some point in their life. But while a powerful technology, genetic testing will always be limited in that it cannot predict exactly what will happen in the future. Because of the world's constantly changing nature, any type of scientific analysis that pertains to the future will never be able to predict coming events with absolute certainty. Therefore, before engaging in susceptibility genetic

testing, consumers must take appropriate measures to ensure that they fully understand the dangers, risks, implications, and limitations associated with such tests. If genetic test consumers choose to disregard this information, they may cause serious psychological distress either to themselves or to those around them. Just like a sharp scalpel in the hands of a surgeon, scientific literacy serves as a powerful and profitable tool when it is intentionally applied by the hands of consumers. Yet just as a scalpel becomes dangerous if it is not maintained or sharpened over time, destructive consequences will ensue if society continues to engage in genetic testing without first endeavoring to maintain an understanding of it.

Note: This essay was originally composed in Dr. Steven Mollmann's AWR 201 class and revised for publication under the guidance of Dr. Nicole Schrag.

Works Cited

Bennett, Christina. "Ambiguous Genetic Test Results Can Be Unsettling. Worse, They Can Lead to Needless Surgeries." *Washington Post*, 7 Feb. 2021, www.washingtonpost.com/health/genetic-tests-uncertain-results/2021/02/05/80a06d9a-65a2-11eb-8468-21bc48f07fe5_story.html.

Berg, Cheryl, and Kelly Fryer-Edwards. "The Ethical Challenges of Direct-to-Consumer Genetic Testing." *Journal of Business Ethics,* vol. 77, no. 1, Jan. 2008, pp. 17–31. *JSTOR*, https://doi.org/10.1007/s10551-006-9298-8.

Broadstock, Marita, et al. "Psychological Consequences of Predictive Genetic Testing: A Systematic Review." *European Journal of Human Genetics,* vol. 8, no. 10, 3 Oct. 2000, pp. 731–738. *PubMed*, https://doi.org/10.1038/sj.ejhg.5200532.

Feetham, Suzanne L., and Elizabeth J. Thomson. "Keeping the Individual and Family in Focus." *Individuals, Families, and the New Era of Genetics: Biopsychosocial Perspectives,* edited by Suzanne M. Miller et al., Norton, 2006, pp. 3–35.

"Genetic Testing: Is It Better Not to Know?" *Consider This* from NPR, hosted by Mary Louise Kelly, 13 May 2022, www.npr.org/transcripts/1098550511.

Haga, Susanne B., et al. "Public Knowledge of and Attitudes toward Genetics and Genetic Testing." *Genetic Testing and Molecular Biomarkers,* vol. 17, no. 4, 26 Mar. 2013, pp. 327–335. *Mary Ann Liebert,* https://doi.org/10.1089/gtmb.2012.0350.

Heshka, Jodi T., et al. "A Systematic Review of Perceived Risks, Psychological and Behavioral Impacts of Genetic Testing." *Genetics in Medicine*, vol. 10, no. 1, Jan. 2008, pp. 19–32. *ScienceDirect*, https://doi.org/10.1097/GIM.0b013e31815f524f.

Hudson, Kathy, et al. "ASHG Statement on Direct-to-Consumer Genetic Testing in the United States." *American Journal of Human Genetics,* vol. 81, no. 3, Sept. 2007, pp. 635–637. *ScienceDirect*, https://doi.org/10.1086/521634.

Kliff, Sarah, and Aatish Bhatia. "When They Warn of Rare Disorders, These Prenatal Tests Are Usually Wrong." *The New York Times,* 1 Jan. 2022, www.nytimes.com/2022/01/01/upshot/pregnancy-birth-genetic-testing.html.

Ogunkola, Babalola J. "Scientific Literacy: Conceptual Overview, Importance and Strategies for Improvement." *Journal of Educational and Social Research*, vol. 3, no. 1, Jan. 2013, pp. 265–274. *ResearchGate*, www.researchgate.net/publication/235329114.

Owczarek, Marcin, et al. "How Is Loneliness Related to Anxiety and Depression: A Population-Based Network Analysis in the Early Lockdown Period." *International Journal of Psychology,* vol. 57, no. 5, 6 May 2022, pp. 585–596. *PubMed Central*, https://doi.org/10.1002/ijop.12851.

Sharkey, Catherine M., et al. "Regulatory and Medical Aspects of DTC Genetic Testing." *Consumer Genetic Technologies: Ethical and Legal Considerations*, edited by I. Glenn Cohen et al., Cambridge UP, 2021, pp. 277–291.

Snow, Catherine E., and Kenne A. Dibner, editors. "Summary." *Science Literacy: Concepts, Contexts, and Consequences,* National Academies Press, 2016, pp. 1–9. *National Library of Medicine*, www.ncbi.nlm.nih.gov/books/NBK396081.

"What Is Genetic Testing?" *MedlinePlus,* National Library of Medicine, 28 July 2021, medlineplus.gov/genetics/understanding/testing/genetictesting.

Zallen, Doris Teichler. *To Test or Not to Test: A Guide to Genetic Screening and Risk*. Rutgers UP, 2008.